# Difficult Diagnoses

## Examining Caregivers' Experiences with Dementia Diagnosis

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## INTRODUCTION

The process of receiving a diagnosis of Alzheimer's disease or a related dementia (ADRD) can be overwhelming and often times frustrating for families. While many caregivers are interested in receiving information about providing care and available resources, they often do not receive them at diagnosis[1, 2, 3].

Without education and information, caregivers are left to fend for themselves in learning about the disease, locating community support, and obtaining assistance in managing care. Once a diagnosis of ADRD is provided there is evidence[1, 4, 5] to suggest that physicians often fail to adequately educate individuals and families about the disease and to establish connections with community resources.

In a recent study using focus groups, physicians acknowledged that they lacked an understanding of the services available to individuals and families, simply stating, "We have not referred any patients; it's usually family members who find these services"[4]. Another study focusing on the caregivers' perspectives found that families believed this type of information should come from their physician[3].

***The purpose of this study was***

1. To learn from family caregivers about the diagnostic process (e.g., diagnosing physician, diagnostic tests utilized) and the length of time that it took to receive a definitive diagnosis of ADRD.

2. To determine whether family caregivers were provided with adequate information about disease processes and community resources.

## METHODS

**Sampling**

The population for this cross-sectional study consisted of family caregivers of individuals with an ADRD diagnosis. Information was presented about the study to caregivers at educational and support meetings run through the Alzheimer's Association Central Ohio chapter. Caregivers who expressed an interest in participating were given the option of either completing a self-administered paper survey or completing the survey online

**Measures**

Measures included in the survey instrument were primarily descriptive and consisted of 25 items. Dichotomous and categorical measures were utilized to explore the experiences and possible needs of caregivers during and following diagnosis.

**Statistical Analysis**

Frequencies, descriptive statistics, and inferential statistics (t-tests) were computed for the quantitative data using SPSS 17.0.

**Limitations**

Limitations included that it was retrospective and lacked racial diversity in study participants. Additionally the study participants only consisted of individuals who had found and accessed services through the Alzheimer's Association.

**Study Demographics**

Caregivers were primarily spouses or partners (50.9%) and adult children (39.6%). Most of the caregivers were white (89.6%) and lived in urban areas (63.3%). Almost half of the caregivers were male (49.1%). The most common diagnoses included AD (53%) and dementia unspecified (16%).

## RESULTS

The final sample consisted of 106 caregivers to persons with a dementia diagnosis (N=106)

**Table 1: Experience with Diagnostic Process**

| Characteristics | % |
|---|---|
| ***Length of time it took to receive diagnosis*** | |
| First doctor's visit | 14.2 |
| 1-3 months of testing | 27.4 |
| 4-6 months of testing | 23.6 |
| 7-12 months of testing | 17.9 |
| 1-2 years of testing | 9.4 |
| More than 2 years of testing | 2.8 |

**Table 2: Knowledge of Caregiving Role**

| Characteristics | % |
|---|---|
| ***At diagnosis, caregiver had information about disease and caregiving role?*** | |
| No | 84.0 |
| Yes | 14.2 |
| ***A year following diagnosis, caregiver had information about disease and caregiving role?*** | |
| No | 49.1 |
| Yes | 44.3 |
| Not applicable, hasn't been one year yet | 4.7 |

**Table 3: Knowledge of Support Services**

| Characteristics | % |
|---|---|
| ***At diagnosis, caregiver had information about available community resources?*** | |
| No | 93.4 |
| Yes | 6.6 |
| ***A year following diagnosis, caregiver had information about available community resources?*** | |
| No | 62.3 |
| Yes | 28.3 |
| Not applicable, hasn't been one year yet | 4.7 |
| ***Doctor referred caregiver to support program at diagnosis*** | |
| No | 63.2 |
| Yes | 35.8 |

In some case, caregivers reported not learning about services at the Alzheimer's Association until over a year after diagnosis (18.9%).

## CONCLUSION

**Discussion**

As the results of this study indicate, family caregivers struggle to obtain the information and support that they need to provide care. Collaborations between health care professionals and community support agencies (i.e. Alzheimer's Association) may be an important bridge mechanism as caregivers move from diagnosis to prolonged care. In the long run, caring for individuals with ADRD is a community responsibility. Approaches that use a comprehensive web of care resources may be the most effective way to help families during and after this most difficult diagnosis.

**Implications**

A key element within these programs[7] is the acknowledgement of time constraints for primary care physicians and the use of interdisciplinary teams during and after the diagnostic process. For instance, one study[8] found that using care management support from nurses or social workers in conjunction with the work and expertise of physicians resulted in higher satisfaction rates for both providers and caregivers, as well as higher rates of compliance with evidence-based guidelines for dementia care.

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*References are available upon request*